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Patients' Lived Experiences of Self-Management in Chronic Kidney Disease Undergoing Hemodialysis: A Qualitative Study

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ABSTRACT

Background: Chronic kidney disease (CKD) patients undergoing hemodialysis (HD) face complex multidimensional challenges that profoundly affect self-management capacity and quality of life.

Purpose: To explore the lived experiences of CKD patients undergoing HD, focusing on self-management practices, perceived barriers and benefits, and educational needs within the Health Belief Model (HBM) framework.

Methods: A qualitative exploratory study was conducted at the Hemodialysis Unit of one of the hospitals in Bukittinggi, West Sumatera, Indonesia. Twenty CKD patients undergoing routine HD were selected using purposive sampling technique. In-depth semi structured interviews were conducted individually (20–45 minutes). Data were analyzed using Braun and Clarke's reflexive thematic analysis approach. Trustworthiness was ensured through source triangulation, member checking, audit trail, and peer debriefing.

Results: Nine themes emerged: (1) physical burden of fatigue, cramps, and activity limitation; (2) psychological adaptation from fear and shock to acceptance; (3) social role disruption and community participation; (4) perceived susceptibility and severity; (5) self-management challenges in diet, fluid restriction, and medication adherence; (6) perceived benefits of adherence; (7) barriers of transportation, economic burden, and vascular access complications; (8) self-efficacy and family support as motivational pillars; and (9) educational needs favoring interactive and personalized approaches.

Conclusion: Patients' self-management experiences are shaped by intersecting physical, psychological, social, and educational dimensions, providing a critical empirical foundation for developing a structured HBM-based Self-Management Education model for the Indonesian hemodialysis context.

Keywords : Chronic Kidney Disease, Hemodialysis, Lived Experience, Qualitative Study, Self-Management

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BACKGROUND

Chronic kidney disease (CKD) is a progressive, irreversible condition defined by persistent kidney damage or a glomerular filtration rate below 60 mL/min/1.73m² for more than three months. Hemodialysis (HD) remains the most widely used modality of renal replacement therapy worldwide. In Indonesia, a multicenter study across tertiary-care centers in Jakarta documented a rapid 84% increase in HD prevalence over five years, reaching 132,000 patients in 2018, with diabetic kidney disease and hypertension as the dominant etiologies (Hustrini et al., 2023). Concurrent national survey data confirm that hypertension, dietary patterns, and lifestyle factors are the primary modifiable risk factors driving CKD progression across 34 Indonesian provinces (Hidayangsih et al., 2023).

HD imposes profound multidimensional burdens on patients, encompassing physical complications such as fatigue, muscle cramps, and dyspnea, as well as psychological distress including anxiety and depression, and altered social roles (Barello et al., 2023; Yasin et al., 2024). Simultaneously, patients must maintain strict self-management regimens involving dietary restrictions, fluid limitations, medication adherence, and vascular access care, while managing coexisting chronic conditions (Liu et al., 2024; Xia & Wang, 2024).

Self-management in HD encompasses all patient-led behaviors aimed at maintaining health between dialysis sessions and is strongly associated with improved quality of life, reduced hospitalization rates, and better clinical outcomes (Almutary & Tayyib, 2021; Safi et al., 2024). However, evidence consistently highlights suboptimal self-management practices among Indonesian HD patients, attributable to inadequate health education, low perceived disease risk, and structural barriers including transportation challenges and economic constraints (Liu et al., 2024; Xia & Wang, 2024).

The Health Belief Model (HBM) provides a robust theoretical framework for understanding and modifying health behaviors in chronic disease, comprising six constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy (Kam & Lee, 2024; Zhang & Xia, 2024). HBM-based interventions have demonstrated consistent effectiveness in improving adherence and self-management behaviors in diverse chronic disease populations (Song et al., 2022). Despite this evidence base, there remains a critical gap in qualitative research exploring patients' subjective lived experiences of HD self-management within the Indonesian context an indispensable first step toward developing contextually appropriate educational interventions. Because nurses are the health professionals in most frequent contact with HD patients and carry primary responsibility for self-management education in dialysis units, such evidence is also essential for strengthening person-centered nursing practice in hemodialysis care more broadly.

This study aimed to explore the lived experiences, self-management practices, perceived barriers and benefits, and educational needs of CKD patients undergoing routine hemodialysis, within the theoretical framework of the Health Belief Model.

METHODS

Design and Setting

This qualitative exploratory study was conducted using a phenomenological approach to capture the depth and richness of patients' subjective experiences of self-management while

undergoing hemodialysis. This design was deemed appropriate given the limited qualitative evidence on patients' lived experiences within the Indonesian hemodialysis context, and its capacity to surface the perceptual and behavioral dimensions underlying the Health Belief Model framework. The study was conducted at the Hemodialysis Unit of RSUD Dr. Achmad Mochtar Bukittinggi, West Sumatra, Indonesia, between April and May 2026. This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

Participants and Sampling

Twenty CKD patients undergoing routine HD were recruited using purposive sampling. Inclusion criteria were: (1) confirmed CKD stage 5 requiring HD, (2) minimum 1 month on routine HD, (3) aged ≥18 years, and (4) able to communicate and provide informed consent. Patients with severe cognitive impairment or acute hemodynamic instability were excluded. Data saturation was achieved at the 17th participant, with three additional interviews conducted to confirm saturation. All 20 eligible patients who were approached agreed to participate, and none declined.

Instruments and Data Collection

In-depth semi-structured interviews were conducted individually at the Hemodialysis Unit, lasting 20–45 minutes per session. An interview guide developed based on HBM constructs covered ten domains: physical condition, psychological state, social functioning, self-management practices, perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and educational needs. Prior to data collection, the content of the interview guide was validated through expert review by three validators: two medical-surgical nursing lecturers from Poltekkes Kemenkes Padang, who contributed academic expertise in the nursing care of patients with chronic kidney disease, and an experienced hemodialysis nurse from RSUD Dr. Achmad Mochtar Bukittinggi, who contributed clinical expertise in the day-to-day care of HD patients. The validators assessed whether each question was relevant to the HBM constructs and the study objectives, whether the wording was clear and understandable for HD patients, and whether the questions were culturally appropriate; their input was used to finalize the interview guide. All interviews were conducted in Bahasa Indonesia, audio-recorded with participants' consent, and supplemented with field notes. Transcripts were produced verbatim by the research team.

Data Analysis

Thematic analysis was conducted following Braun and Clarke's reflexive thematic analysis approach (Byrne, 2022), following six phases: (1) data familiarization, (2) open coding, (3) category grouping, (4) theme development, (5) theme review and refinement, and (6) report writing. Trustworthiness of the analytical process was upheld through systematic documentation and transparency at each analytical stage (Nowell et al., 2017). Two researchers independently coded all transcripts; discrepancies were resolved through consensus discussion. Trustworthiness was further established through source triangulation, member checking, an audit trail, and peer debriefing.

Ethical Considerations

This study received ethical approval from the Health Research Ethics Committee (KEPK) of Universitas Perintis Indonesia, Number: 1595/KEPK.F1/ETIK/2026, Protocol No.:

26-03-1982, dated 26 March 2026 (KEPPKN Validation No.: 0116221371). All participants provided informed consent before the interviews, and confidentiality was maintained by using participant codes (P1–P20) instead of names.

RESULTS

Twenty patients participated in the study. Participant characteristics are presented in Table 1. The sample comprised both male and female patients, with ages ranging from 30–39 to 60–69 years (10-year bands) and HD duration ranging from 1 to 72 months. Comorbidities included diabetes mellitus, hypertension, stroke, and kidney stones. Vascular access included central dialysis catheters (CDL) and arteriovenous fistulas (Cimino). Thematic analysis yielded nine main themes, summarized in Table 2 together with their mapping onto the six HBM constructs.

Table 1. Characteristics of Study Participants (n=20)

Code	Sex	Age (years)	Occupation	HD Duration (months)	Vascular Access	Comorbidity
P1	Female	50–59	Homemaker	6	CDL	DM, HT
P2	Female	30–39	Homemaker	36	Cimino (AV fistula)	CKD stage 5
P3	Female	60–69	Homemaker	24	CDL	CKD, post-op
P4	Female	50–59	Homemaker	>60	CDL	CKD
P5	Male	40–49	Self-employed	6	Cimino	CKD
P6	Female	40–49	Teacher	24	Cimino	CKD
P7	Female	60–69	Homemaker	36	CDL	CKD, stroke
P8	Male	30–39	Unemployed	1	CDL	CKD
P9	Male	50–59	Self-employed	3	CDL	DM, CKD
P10	Male	60–69	Retired	6	CDL	CKD
P11	Female	40–49	Homemaker	3	CDL	CKD
P12	Male	50–59	Unemployed	6	CDL	DM, CKD
P13	Male	60–69	Retired	72	Cimino	CKD, stroke
P14	Female	40–49	Homemaker	24	Cimino	HT, CKD (preeclampsia history)
P15	Female	50–59	Former farmer	48	Cimino	CKD (kidney stones)
P16	Male	40–49	Unemployed	12	Cimino	DM, CKD
P17	Male	40–49	Self-employed	48	Cimino	CKD
P18	Female	60–69	Homemaker	72	Cimino	CKD
P19	Male	50–59	Self-employed	3	CDL (femoral)	DM, CKD
P20	Female	40–49	Homemaker	6	CDL	DM, HT, CKD

Note. CDL = Central Dialysis Line; DM = Diabetes Mellitus; HT = Hypertension. CKD = Chronic Kidney Disease; HD = Hemodialysis; AV = Arteriovenous. Age is presented in 10-year bands; HD duration is presented in months for all participants (>60 = more than five years).

Table 2. Summary of Themes, Categories, and Corresponding HBM Constructs from Thematic Analysis (n=20)

No	Theme	Categories	HBM Construct(s)	Sources
T1	Physical burden: fatigue, cramps, and activity limitation	Muscle cramps; dizziness; dyspnea; reduced physical capacity; sleep disturbance	**Perceived severity** Perceived barriers	All (n=20)
T2	Psychological adaptation: from fear and shock to acceptance	Initial fear/shock; denial; reframing HD as obligation or motivation; spiritual coping	**Perceived severity** Self-efficacy	P2,P7,P10,P14,P17,P20
T3	Social role disruption and community participation	Reduced occupational capacity; altered family role; maintained vs limited community participation	**Perceived severity** Perceived barriers	All (n=20)
T4	Perceived susceptibility and severity: understanding disease risk	Awareness of HD consequences; understanding disease seriousness; evolving risk perception; delayed help-seeking	**Perceived susceptibility** Perceived severity; Cues to action	P1,P9,P11,P14,P16,P17
T5	Self-management challenges: diet, fluid restriction, and medication adherence	Fluid restriction difficulty (severe thirst); dietary non-adherence; medication adherence; family monitoring dependence	**Perceived barriers** Cues to action	P1,P2,P5,P12,P14,P15,P17,P20

No	Theme	Categories	HBM Construct(s)	Sources
T6	Perceived benefits: positive outcomes of adherence	Improved well-being; weight gain; reduced hospitalization; resolution of edema; skin improvement	**Perceived benefits**	P1,P5,P6,P7,P8,P9,P19
T7	Barriers: transportation, economic burden, and vascular access issues	Transportation distance; economic disruption; access complications; repeated surgeries; social stigma	**Perceived barriers**	P1,P5,P6,P12,P13,P16,P19,P20
T8	Self-efficacy and family support as motivational pillars	Children as primary motivation; family as monitoring agent; active independence; spiritual acceptance	**Self-efficacy** Cues to action	P5,P9,P14,P17,P18,P19
T9	Educational needs: preference for interactive and personalized approaches	Active inquiry preference; specific dietary education need; satisfaction with bedside education	**Cues to action**	P1,P6,P10,P11,P18

Note. HBM = Health Belief Model. HD = Hemodialysis; P = participant code; T = theme. Bold = primary HBM construct reflected by the theme; non-bold = secondary construct(s). Themes describing the broader illness experience (T1–T3) and educational needs (T9) were mapped to the construct(s) they most directly inform.

As shown in Table 2, all six HBM constructs were represented in the data. Perceived susceptibility was captured by T4; perceived severity by T1–T4, reflecting the physical, psychological, and social consequences of CKD and HD; perceived benefits by T6; perceived barriers by T1, T3, T5, and T7; cues to action by T4 (clinical deterioration and physicians' explanations), T5 (adverse bodily effects following dietary transgressions), T8 (children and

family members), and T9 (nurse-delivered education); and self-efficacy by T2 and T8. The mapping was therefore not one-to-one: several themes informed more than one construct, and each construct was supported by at least one theme.

Theme 1: Physical Burden → Fatigue, Cramps, and Activity Limitation.

All participants reported significant physical burdens associated with HD. Muscle cramps, dizziness, and dyspnea were the most frequently reported symptoms, typically intensifying during the inter-dialytic period. These symptoms progressively constrained daily functioning, reducing capacity for household tasks, occupational activities, and physical mobility. Sleep disturbance emerged as an underreported yet significant complication, particularly among newer HD patients.

"Waktu mau cuci darah, badan terasa kram, pusing, dan jalan pun terasa berat." **[P1]**
("Before dialysis, my body feels cramped, dizzy, and walking feels heavy.")

"sangat susah tidur kalau malam hari, terkadang sampai sakit kepala karena kurang tidur." **[P20]**
("I have great difficulty sleeping at night, sometimes getting headaches from sleep deprivation.")

For patients with comorbid stroke (P7, P13), physical limitations were compounded, resulting in complete functional dependence on family members.

Theme 2: Psychological Adaptation → From Fear and Shock to Acceptance.

A consistent psychological trajectory was identified across participants: initial fear, shock, or denial at diagnosis, followed by varying degrees of acceptance and adaptation. The emotional intensity of initial responses ranged from mild apprehension to profound distress.

"Pertama kali rasanya takut, karena namanya cuci darah pasti menakutkan. Dulu badan dan pikiran rasanya sulit menerima kondisi ini." **[P2]**
("The first time, I was afraid, the word 'dialysis' is frightening. Before, my body and mind couldn't accept this condition.")

Over time, patients reframed HD as a normalized routine or life-sustaining commitment, facilitated by tangible clinical improvements. This cognitive reframing was instrumental in sustaining adherence.

"Sekarang saya anggap cuci darah ini seperti jadwal anak sekolah saja; kalau sudah jadwalnya, ya berangkat." **[P2]**
("Now I treat dialysis like a child's school schedule; when it's time, you go.")

"Saya menganggap cuci darah ini adalah bagian dari usaha saya untuk sehat. Jadi saya menjalaninya dengan senang hati." **[P10]**
("I regard dialysis as part of my effort to be healthy. So I go through it willingly.")

Theme 3: Social Role Disruption and Community Participation.

HD exerted significant impact on social functioning and community roles. Changes in occupational capacity and family roles were universally reported. Most participants could no longer engage in their previous employment or perform physically demanding household tasks.

"Perubahannya sangat terasa. Perekonomian lebih terganggu karena sekarang tidak bisa mencari nafkah lagi." **[P12]**

("The change is very noticeable. Economically we are more disrupted because I can no longer earn income."). Despite role disruption, the majority of participants actively resisted social isolation, continuing to attend community events, prayers, and family gatherings. This active maintenance of social participation was perceived as emotionally protective.

"Saya tetap pergi. Jadi tidak ada pengaruhnya terhadap rutin harian, saya tidak terus-terusan mengurung diri di rumah." **[P5]**

("I still go. So it doesn't affect my daily routine; I don't shut myself in at home.")

Theme 4: Perceived Susceptibility and Severity → Understanding Disease Risk.

Patients' perceptions of susceptibility and severity evolved significantly throughout their HD experience. Initial diagnoses were frequently met with disbelief; however, direct experience of missed-session consequences rapidly heightened perceived risk.

"Itu racun di badan tidak bisa keluar, kan?" **[P1]**

("The toxins in the body cannot come out, right?")

"Dokter bilang fungsi ginjal saya tinggal 5% dan harus segera cuci darah." **[P14]**

("The doctor said my kidney function is only 5% and I must start dialysis immediately.")

Several participants (P11, P17) described an initial phase of low perceived susceptibility, during which they delayed seeking medical care and first attempted traditional herbal remedies. Direct physical deterioration including haemoglobin levels falling to 6 g/dL (P17), ultimately prompted engagement with biomedical treatment.

Theme 5: Self-Management Challenges → Diet, Fluid Restriction, and Medication Adherence.

Self-management challenges were universal, with fluid restriction emerging as the single most difficult component. Severe thirst drove repeated violations of fluid limitations, even among highly motivated participants.

"yang paling sulit dikontrol adalah minum. Rasanya haus sekali dan ingin minum banyak, susah untuk menahannya." **[P15]**

("What is most difficult to control is drinking. I feel so thirsty and want to drink a lot, it's hard to restrain myself.")

"yang paling sulit dikontrol adalah minum. Rasanya haus sekali, saya bisa minum lebih dari dua gelas sehari." **[P20]**

("Fluid control is hardest. I feel so thirsty I sometimes drink more than two glasses a day.")

Dietary restrictions were generally better managed, though occasional transgressions occurred, typically reversed by immediate adverse consequences experienced.

"Kadang-kadang sulit menahan diri, tapi kalau sudah terasa efeknya di badan, saya jadi kapok." **[P12]**

("Sometimes it's hard to restrain myself, but when I feel the effects on my body, I learn my lesson.")

Family members, particularly spouses, served as critical external monitoring agents. In several cases, families fully managed dietary preparation and fluid measurement, creating dependent rather than autonomous self-management systems.

"Istri saya di rumah yang menjadi 'perawatnya', dia yang menakar dan menyiapkan semuanya." **[P5]**
("My wife at home is the 'nurse', she measures and prepares everything.")

Theme 6: Perceived Benefits → Positive Outcomes of Adherence.

Despite HD burdens, participants consistently identified substantial perceived benefits from adherence, which functioned as powerful motivators sustaining long-term behavioral compliance.

"Alhamdulillah, justru badan terasa tambah sehat dan terasa lebih ringan." **[P9]**
("Alhamdulillah, my body actually feels healthier and lighter.")

"Alhamdulillah badan terasa jauh lebih baik dibandingkan dulu saat kondisi saya sedang drop. Berat badan saya juga bertambah sekitar 20 kg." **[P5]**
("My body feels much better than when I was in critical condition. I have also gained about 20 kg.")

Specific benefits included reduction in dyspnea, decreased hospitalization frequency, resolution of peripheral edema, improved appetite, and enhanced skin appearance (P19). All participants compared their current status favorably to their pre-HD condition, reinforcing the motivational centrality of perceived benefits in sustaining adherence.

Theme 7: Barriers to Self-Management → Transportation, Economic Burden, and Vascular Access Issues.

Multiple structural and clinical barriers impeded optimal self-management. Transportation to the dialysis facility was the most consistently reported logistical challenge, particularly for patients in remote and peri-urban areas of West Sumatra.

"Kendalanya paling di transportasi, karena jaraknya cukup jauh dan terkadang transportasinya sulit atau lambat." **[P5]**
("The main challenge is transportation, the distance is quite far and sometimes transport is difficult or slow.")

Economic disruption was a significant barrier for participants who had been the primary family breadwinner, creating cascading financial hardship. Vascular access complications constituted a major clinical barrier, including CDL water exposure precautions, repeated surgical revisions (P13, P20), venepuncture difficulty (P6), and social stigma from visible access devices.

"Yang agak mengganggu itu kalau orang melihat akses di tangan, rasanya tidak nyaman." **[P1]**
("What bothers me somewhat is when people see the access on my hand, it feels uncomfortable.")

"Rasanya ngeri karena sudah tiga kali dioperasi. Saya merasa takut setiap kali harus operasi lagi." **[P20]**
("It feels dreadful, I've already had three operations. I feel afraid every time I need another surgery.")

Theme 8: Self-Efficacy and Family Support as Motivational Pillars.

Self-efficacy was a salient theme across participants. The most universal and powerful source of self-efficacy was responsibility toward children, consistently expressed across diverse participants regardless of sex, age, or duration of HD.

> *"Anak-anak saya. Saya memiliki tiga orang anak... Saya merasa mereka masih sangat membutuhkan saya, itulah alasan utama saya harus tetap kuat dan semangat."* **[P17]**
> ("My children. I have three children... I feel they still need me greatly, that is the main reason I must stay strong and motivated.")
> *"Anak-anak adalah penyemangat saya. Saya harus bertahan dan sehat agar bisa melihat mereka sampai besar."* **[P14]**
> ("My children are my motivation. I must survive and stay healthy to see them grow up.")

Maintaining active independence was an important protective strategy. Participants who remained active through employment, light physical activity, or community participation consistently reported higher perceived self-efficacy and lower psychological distress.

> *"Saya tidak mau hanya duduk diam di rumah, karena kalau tidak ada kegiatan, saya malah jadi stres dan banyak pikiran. Dengan beraktivitas dan bekerja, saya merasa lebih semangat dan produktif."* **[P17]**
> ("I don't want to just sit at home, if I'm not active, I become stressed and overthink. By staying active and working, I feel more motivated and productive.")

Theme 9: Educational Needs → Preference for Interactive and Personalized Approaches.

Participants' educational needs revealed important implications for intervention design. The predominant preference was for interactive, bidirectional education rather than passive information delivery. Active inquiry was valued as the primary mechanism for information acquisition.

> *"Kalau soal edukasi, awalnya perawatnya ada yang pendiam, jadi kita harus rajin bertanya apa yang kurang atau apa yang harus dilakukan."* **[P1]**
> ("Regarding education, some nurses were initially quiet, so we had to actively ask what was needed to be done.")

Specific dietary education was the most frequently requested content. Notably, most experienced participants explicitly opposed dedicated educational classes, citing the importance of preserving inter-dialytic rest time.

> *"Saya rasa tidak perlu ada kelas khusus, karena waktu itu lebih baik digunakan pasien untuk istirahat. Edukasi yang diberikan secara langsung saat perawatan seperti sekarang ini sudah sangat pas dan cukup bagi kami."* **[P10]**
> ("I don't think a special class is needed, that time is better used for rest. Education given directly during treatment is already very appropriate and sufficient.")

DISCUSSION

This study provides a comprehensive qualitative account of the lived experiences of CKD patients undergoing HD in an Indonesian regional referral hospital. The nine themes identified map onto all six HBM constructs (Table 2), affirming the theoretical congruence of HBM for understanding and intervening in self-management behaviors in this population. Notably, the mapping was not one-to-one: themes describing the broader illness experience

(T1–T3) simultaneously informed perceived severity and perceived barriers, whereas children and family (T8) and bedside education (T9) functioned as key external cues to action. This multi-construct pattern suggests that HBM-based education should address the constructs in combination rather than in isolation.

The physical burdens documented in Theme 1 (perceived severity and perceived barriers), particularly inter-dialytic fatigue, cramps, and sleep disturbance are consistent with prior systematic reviews reporting fatigue and sleep disorders as the most debilitating symptoms in HD patients (Barello et al., 2023). Notably, sleep disturbance, while prevalent across participants, has received limited attention as a self-management target in educational interventions and represents a priority area for the forthcoming SME–HBM model.

The psychological trajectory identified in Theme 2 (perceived severity and self-efficacy), from fear and shock to acceptance parallels established models of adjustment to chronic illness. Spontaneous cognitive reframing strategies, such as normalizing HD as a routine obligation or life-sustaining investment, appear central to sustaining long-term adherence (Almutaryet al., 2023). This finding underscores the importance of integrating psychological support from the earliest stage of HD initiation, rather than addressing psychological barriers only after behavioral non-adherence has been established. From an HBM perspective, this reframing reflects growing self-efficacy, as patients come to perceive themselves as capable of sustaining the HD regimen.

Themes 4 (perceived susceptibility and severity), 5 (perceived barriers and cues to action), and 6 (perceived benefits) collectively illuminate the complex temporal interplay of HBM constructs. Low perceived susceptibility during early illness (Theme 4) contrasts sharply with strong perceived benefits reported by experienced patients (Theme 6). This temporal shift has direct implications for educational timing: interventions targeting perceived susceptibility and severity are most critical during the HD induction phase, while educational strategies emphasizing perceived benefits are more resonant for long-term adherents (Kam & Lee, 2024; Keivan et al., 2023; Zhang & Xia, 2024).

The finding that fluid restriction is the most challenging self-management behavior (Theme 5) is consistent with the broader HD literature (Xia & Wang, 2024). Crucially, however, our data reveal that severe physiological thirst not simply insufficient knowledge or motivation is the primary driver of fluid non-adherence. In HBM terms, thirst operates as a dominant perceived barrier, whereas the immediate bodily consequences of dietary transgressions acted as internal cues to action that prompted patients to restore adherence. This finding suggests that educational interventions alone are insufficient; HBM-based education must be complemented by practical fluid management strategies addressing the physiological substrate of non-adherence (Ouirdani et al., 2024).

The structural barriers identified in Theme 7 (perceived barriers), transportation, economic disruption, and vascular access complications reflect the broader social determinants of health constraining self-management capacity in lowand middle income settings (Hidayangsih et al., 2023). An exclusively knowledge-based educational model is unlikely to achieve sustained behavioral change in contexts characterized by significant socioeconomic vulnerability.

The centrality of family support (Theme 8; self-efficacy and cues to action) warrants particular attention in intervention design. Children and family members functioned as powerful external cues to action, reminding and motivating patients to adhere to their regimen. While family support clearly enhances adherence, our data reveal that it can substitute for, rather than build, patient self-efficacy, particularly for dietary management (P5, P13). An effective SME - HBM model must therefore engage family members as active co-participants while simultaneously fostering patient autonomy. This aligns with KDIGO 2022 recommendations for person-centered, family-inclusive CKD care ("KDIGO 2022 Clinical Practice Guideline for Diabetes Management in Chronic Kidney Disease," 2022) and with evidence demonstrating that educating family caregivers of HD patients significantly reduces caregiver burden and improves patient adherence (Hayati et al., 2023).

Finally, the interactive and context-sensitive educational preferences expressed in Theme 9 (cues to action) provide critical design parameters for the SME-HBM model. Bedside education delivered by nurses served as an important external cue to action, suggesting that this channel should be strengthened rather than replaced by separate classes. Structured self-management training programs in naturalistic clinical settings have demonstrated significant effectiveness in improving self-efficacy, knowledge, and adherence in HD patients (Aljawadi et al., 2024; Liu et al., 2024). The integration of HBM principles into interactive, bedside-integrated educational delivery represents a theoretically sound and practically feasible approach for this population (Ouirdani et al., 2024; Song et al., 2022). Furthermore, health literacy and self-efficacy have been identified as key mediators of health outcomes among HD patients, reinforcing the need for educational models that simultaneously address both cognitive and motivational dimensions of self-management (Hsu et al., 2024).

Limitations

This study was conducted in a single hemodialysis unit in West Sumatra, Indonesia. Therefore, the findings reflect the experiences of patients in this regional setting and may not be transferable to other regions or health-care settings with different cultural and structural characteristics.

Implications for Nursing Practice

Key implications for nursing practice include: integrating psychological adaptation support from HD initiation; prioritizing practical fluid management strategies alongside patient education; involving family members as active educational co-participants while building patient self-efficacy; addressing structural barriers in intervention design; and adopting interactive, bedside-integrated educational delivery aligned with patients' expressed preferences. Future research should test the effectiveness of the SME–HBM model through a quasi-experimental design measuring quality of life, health beliefs, self-efficacy, and self-management outcomes.

CONCLUSION

This qualitative study provides a rich, contextually grounded account of the lived experiences of CKD patients undergoing HD in Indonesia. Nine themes spanning physical burden, psychological adaptation, social role disruption, perceived susceptibility and severity, self-management challenges, perceived benefits, structural barriers, self-efficacy and family

support, and educational needs collectively delineate the multidimensional landscape of self-management in this population.

These findings directly inform the development of a structured HBM-based Self-Management Education model tailored to the Indonesian hemodialysis context.

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AUTHOR CONTRIBUTIONS

Yosi Suryarinilsih: Conceptualization, Methodology, Formal analysis, Writing - original draft, Funding acquisition. Sila Dewi Anggreni: Formal analysis, Writing - review and editing. Eka Gusti: Investigation, Validation, Writing - review and editing. All authors read and approved the final manuscript and agree to be accountable for all aspects of the work.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DECLARATION OF AI USE

During manuscript preparation and revision, the authors used Claude (Anthropic; Claude Opus 5.5) for English-language editing and for organizing revisions in response to reviewers' comments. The authors reviewed and edited the output and remain responsible for the content and integrity of the article.

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